

The Concept of Advocacy for people with
Learning Disabilities in Ireland

Author: Gina McNamara

**(BA Honours in Applied Social Studies in Social
Care)**

Submitted to

National University of Ireland, Galway

on behalf of

MA in Public Advocacy and Activism

under

The Huston School of Film and Digital Media

Supervisor: Dr. Andrew Power

August 2009

Table of contents

Acknowledgements.....	2
Abstract.....	3
Introduction to Dissertation.....	4
Chapter 1: Types and Principles of Advocacy.....	8
1 Introduction.....	8
1.1 Components of advocacy.....	8
1.2 Types of advocacy.....	10
1.2.1. <i>Self-advocacy</i>	11
1.2.2. <i>Group advocacy</i>	13
1.2.3. <i>Citizen advocacy</i>	13
1.3 Representative advocacy.....	15
1.3.1. <i>Peer advocacy</i>	15
1.3.2. <i>Family advocacy</i>	16
1.3.3. <i>Legal advocacy</i>	16
1.4 Principles.....	17
1.4.1. <i>Empowerment</i>	17
1.4.2. <i>Autonomy</i>	18
1.4.3. <i>Inclusion</i>	19
1.4.4. <i>Citizenship</i>	19
1.5 Conclusion.....	20
Chapter 2: The Development of Advocacy from an international level to a national level.....	21
2 Introduction.....	21
2.1 Independent Living movement.....	21
2.1.1. <i>International Perspective</i>	21
2.1.2. <i>National Perspective</i>	25
2.2 Disability Rights Movement.....	27
2.2.1. <i>Rights for people with learning disabilities</i>	28
2.2.2. <i>Paradigm shift from the medical model to the social model of disability</i>	29

2.2.3.	<i>Self-advocacy and citizens advocacy</i>	30
2.3	International Legislation.....	31
2.3.1.	<i>UN Convention on the Rights of Persons with Disabilities 2006</i>	31
2.4	Conclusion.....	33
Chapter 3: The current situation of Advocacy in Ireland		34
3	Introduction.....	34
3.1	The development of advocacy through the CIB.....	34
3.1.2.	<i>The three strands to develop advocacy services</i>	37
3.1.3.	<i>Community and Voluntary Programme</i>	37
3.1.4.	<i>Personal Advocacy Service (PAS)</i>	38
3.1.5.	<i>Community Visitors Programme</i>	39
3.2.	Organisations contribution to advocacy.....	40
3.2.1.	<i>National Disability Authority (NDA)</i>	40
3.2.2.	<i>People with Disabilities Ireland (PwDI)</i>	41
3.2.3.	<i>Inclusion Ireland</i>	42
3.2.4.	<i>National Federation of Voluntary Bodies</i>	43
3.3	Best practice Guidelines for advocates.....	44
3.4.	Impact of the current economic crisis on Advocacy Provision	45
3.5	Conclusion.....	46
Chapter 4: Overall findings of this Research		47
4.	Introduction.....	47
4.1.	What is advocacy and what are the main purposes of advocacy?	47
4.2.	What are the common challenges of accessing advocacy services from the viewpoint of a person with learning disabilities?	48
4.2.1.	<i>Paradigm shift from the medical model to the social model of disability</i>	49
4.2.2.	<i>Lack of Support</i>	50
4.2.3.	<i>Attitude Problems</i>	50
4.2.4.	<i>Communication</i>	51
4.2.5.	<i>Lack of Independent Services</i>	51

4.3.	What are the necessary actions required to enhance advocacy services for people with learning disabilities?.....	52
4.3.1.	<i>Promote self-advocacy</i>	52
4.3.2.	<i>Provide more resources</i>	53
4.3.3.	<i>Provide advocacy training</i>	54
4.3.4.	<i>Ensuring advocacy services are completely independent from service providers</i>	54
4.4.	Conclusion.....	55
Chapter 5: Recommendations and Conclusions		56
5	Introduction.....	56
5.1.	Recommendations for further research.....	56
5.2.	Conclusions	57
Bibliography.....		59
Appendix.....		64

Acknowledgements

The author would like to thank all the participants of this dissertation for making this research project possible.

A special thank you goes to my supervisor, Dr. Andrew Power for all the guidance and support which enabled the author to complete this dissertation.

To all the library staff in NUI, Galway, appreciation and gratitude is given for their support in assisting the author on accessing all relevant literature for this project.

Finally, a special thank you goes to my parents and friends for their continued support and advice.

Abstract

Advocacy is a relatively new concept in the disability sector in Ireland. The sole aim of this dissertation is to explore the concept of advocacy for people with learning disabilities.

In order to explore the concept of advocacy, we will identify and discuss some key definitions of advocacy and the main types and principles of advocacy. Following on from this, we will discuss the development of advocacy both nationally and internationally.

This dissertation involved two inter-related methods that took the form of desk-based research and qualitative research. The first three chapters are based on the desk-based research, whereas the fourth chapter is based on the qualitative research and the final chapter consists of recommendations for further research and conclusions for this project.

The qualitative research consisted of seven interviews and one focus group. The participants were mainly from the Brothers of Charity Services and the Citizens Information Board.

The main finding from this research is that advocacy only began to develop since 2000 but there is still a lot of work to be done to ensure people with learning disabilities get their voices heard.

Introduction to Dissertation

The term Advocacy comes from the Latin word 'ad voce' meaning 'towards a voice.' Advocacy is a relatively new concept in the disability sector in Ireland since 2000. Hence, the key interpretation of advocacy is empowering a person to have a voice. Advocacy tends to be widely misunderstood by many professionals among the multidisciplinary team in the disability sector in Ireland. This tends to be due to a lack of information and awareness regarding the process of advocacy.

Advocacy is made up of two components: self-advocacy and representative advocacy. Self-advocacy occurs when a group or an individual are capable of speaking up for themselves whereas representative advocacy involves an advocate speaking up on behalf of a group or individual. Both of these components are reiterated in the following three definitions below:

1. *"Advocacy is actively supporting a cause or issue; speaking up in favour of; recommending; supporting or defending; arguing on behalf of oneself or on behalf of another."*¹
2. *"Advocacy is a means of supporting or speaking up for someone, their needs and rights. It can involve pleading their case on behalf of the person with a disability, or supporting them to speak up for themselves."*²
3. *"Advocacy is about making sure that everyone has an equal voice. Advocacy is also about speaking up and getting someone to listen to you."*³

The importance of advocacy in terms of having a voice and creating the opportunity to speak up whether people are self-advocates or representative advocates are emphasised in the above definitions. However, the meaning of advocacy covers a broad spectrum. The National Disability Authority (NDA)

¹ Birmingham, D. (2001). Forum for People with Disabilities. 2.2 pg. 9

² Comhairle (2004). Goodbody Economic Consultants Report. Vol 1. pg. 12.

³ NDA (2001) pg. 6 and 7

definition differs from the definitions put forward by the Goodbody report (2004) Vol.1 and Birmingham (2001) in that it does not mention the two main components.

This dissertation will endeavour to provide a clearer understanding of the concept of advocacy.

Aims:

- To investigate the concepts and challenges of advocacy from the perspective of people with learning disabilities and to explore recommendations to enhance advocacy services in Ireland from the perspective of people with learning disabilities.

Objectives:

- To explore the development of advocacy provision at an international and national level by looking at the law, policy and practice.
- To identify the common challenges and the necessary actions to enhance advocacy services for people with learning disabilities.

Research Questions:

1. What is advocacy and what are the main purposes of advocacy?
2. What are the common challenges of accessing advocacy services from the viewpoint of a person with a learning disability?
3. What are the necessary actions required to enhance advocacy services for people with learning disabilities?

Methodology:

This research involved two inter-related methods that took the form of desk-based research and qualitative research.

The desk-based research was the initial phase of this dissertation. This involved a comprehensive review of national and international advocacy materials in order to provide an analysis of the concept of advocacy locally, nationally and internationally in order to provide a clearer understanding of advocacy.

This research will focus on advocacy for people with learning disabilities, as they tend to be the most vulnerable group in the disability sector in Ireland. There is a great need to conduct research in this area, as it has not been done to this extent in Ireland up to this point.

This dissertation will use the term 'learning disability' as this is the preferred terminology expressed by participants who took part in this research.

The qualitative method consisted of seven interviews and one focus group. All these interviews were recorded with permission from participants with the exception of the focus group due to the sensitive nature of the issues for the members involved. The participants of this research included the following:

Research Participants	Participants code
Staff member – Brothers of Charity Galway	P1
Staff member – Brothers of Charity Waterford	P2
Galway Advocacy Service – Independent Advocate	P3
National Federation of Voluntary Bodies	P4
Self-advocate – Brothers of Charity Galway	P5
Service Users Council – Focus group Brothers of Charity Galway	P6
Area Executive Officer – Citizens Information Board Galway	P7
Advocacy Officer – Citizens Information Board Dublin	P8

Table 1: Codes for participants referred to in the text.

Structure of Dissertation:

Chapter one in this dissertation will identify and discuss the main types and principles of advocacy with reference to the two components of advocacy.

Chapter two will examine the international and national developments of advocacy by discussing the independent living movement, disability rights movement and the UN Convention on the Rights for Persons with Disabilities.

Chapter three will explore the development of advocacy in Ireland up to this point since the establishment of the Citizens Information Board (CIB).

Chapter four will discuss the main findings from the qualitative research.

Finally, chapter five will identify some key recommendations for further research and will outline the conclusions to this dissertation.

Chapter 1:

Types and Principles of Advocacy

1 Introduction:

This chapter will identify and discuss the main types and principles of advocacy with reference to the two components; self-advocacy and representative advocacy. These types and principles apply to all advocates both nationally and internationally. This chapter will focus on the types and principles of advocacy put forward in the Goodbody report (2004) Vol. 1.

Firstly, this chapter will briefly outline the two components of advocacy. Before we do this, it is vital to discuss briefly the concept of advocacy, which will lead on to discussing the two main components.

Secondly, this chapter will identify and discuss the main types of advocacy.

Finally, this chapter will identify and discuss the four main principles required to enhance the process of advocacy for people with learning disabilities.

1.1 Components of advocacy:

Advocacy is a relatively new concept in the disability sector in Ireland. Woods (2004) indicates that the term advocacy has crept into common parlance only within the last ten years in Ireland. However, the term has been in place in England for at least a period of twenty five years. Also, its implementation has been ineffective due to “the lack of clear strategies” relating to the concept of advocacy.⁴ Woods also argues that many people tend to be put off by the term “advocacy”. Gray and Jackson (2002) believe this is due to the lack of clarity with regards to the definition of advocacy across the board. It appears that there tends to be confusion with regards to advocacy due to the lack of transparency.

⁴ Lishman (2007) pg. 278

While Tufail and Lyon (2007) believe that the salient point of advocacy is to speak up for ones self or others, on the other hand, Stone (1999) emphasises that advocacy empowers people with a learning disability as they should be regarded as “people with power, rights and values.”⁵ This reveals that advocacy is a broad concept, which will become more evident when we discuss the types and principles of advocacy.

Self-advocacy and representative advocacy are the two main components that are persistently reiterated in the definitions of advocacy that are identified in the introduction. Lishman (2005) refers to representative advocacy as a “direct” means of advocacy such as applying for social welfare payments, whereas self-advocacy refers to an “indirect” means of advocacy such as providing accessible information pertaining to the individual’s basic rights and entitlements.

However, Stone (1999) puts forward a unique model of recounting the two components of advocacy. These consist of the following:

- ‘Standing behind’
- ‘Standing before’
- ‘Standing beside’

Stone indicates that ‘standing behind’ refers to self-advocacy by which an advocate supports a person or a group to speak up for themselves. For example, the self-advocacy council within the Brothers of Charity Galway Services has a designated advocacy coordinator to support the group. The group “seeks to empower people to speak up for themselves, develop their confidence, and enable them to get their voices heard.”⁶ On the other hand, Stone refers to ‘standing before’ as a means of representative advocacy. The advocate speaks on behalf of a people who are incapable of speaking up for themselves. For example, the Galway Advocacy Service is an independent

⁵ Stone (1999) pg.29

⁶ Brothers of Charity Galway services Annual Report 2007 pg. 22.

advocacy service that aims to support and represent people with disabilities who struggle to speak up for themselves.⁷

Finally, 'standing beside' is referred to an advocate who assists a person with a disability to speak up for their rights and entitlements by providing a level of moral support. This involves working in partnership together and forming a trustworthy relationship. One example would be that the advocate and the individual or group attend meetings together. This approach can be applied to all the types of advocacy identified above. However, it tends to relate more to self-advocacy and citizens advocacy, which we will discuss in more detail in the next section.

Stone's model demonstrates a clearer understanding of the components of advocacy whereas, Lishman believes that representative advocacy is "direct" and self-advocacy is "indirect". This is not always true as they can be a combination of direct and indirect means of advocacy. This will become more evident as we discuss the types of advocacy separately.

1.2 Types of advocacy:

Self-advocacy

1. Self-advocacy
2. Citizen advocacy
3. Group advocacy

Representative advocacy

1. Peer advocacy
2. Family advocacy
3. Legal advocacy

⁷ Galway Advocacy Service: <http://galwayadvocacyservice.ie/serviceaims.htm>

1.2.1 Self-advocacy:

As mentioned in the first section, self-advocacy is about speaking up for ones self or others in regards to their rights and entitlements. At the first international Peoples First conference held in the USA, a group of people with learning disabilities were inspired to set up a Peoples First organisation in London. This organisation promotes self-advocacy for people with learning disabilities. However, Ramcharan et al (1997) notes that despite the formation of this organisation, the development of self-advocacy has been very slow in terms of setting up self-advocacy groups. Nevertheless, the foundation of this organisation has inspired the further development of the self-advocacy movement throughout England. *Peoples First* describe self-advocacy as follows:

- “Speaking for yourself.
- Standing up for your rights.
- Making choices
- Being independent
- Taking responsibility for yourself.”⁸

This appears to be a clear definition of self-advocacy as it is laid out in a straightforward way. It identifies the salient points reiterated by many of the participants for this research. An example of some of the participants responses consist of the following:

- “Advocacy is about giving a voice to people who have no voice.” P3
- “The purpose of advocacy is to ensure that we can live independent and speak up for ourselves.” P5

Gray and Jackson (2002) emphasise the importance of developing self-advocacy as they consider it to be the most important form of advocacy for people with learning disabilities. Lishman (2007) also reiterates this point

⁸ Peoples First (1993a) cited in Gray & Jackson (2002) pg. 122

by stating that it is the most “fundamental and preferred type of advocacy.”⁹ On the other hand, Lundstrom (2008) and Atkinson (1999) agree with this point to a certain extent, but it is significantly taken for granted by many people in society. Nevertheless, this does not undermine the fantastic work that self-advocates are currently undertaking in speaking up for themselves and others with regards to accessing their rights and entitlements. For example, Lundstrom (2008) conducted a research project to investigate the number of self-advocacy initiatives that exist in Ireland for people with learning disabilities.

Having read this report, there tends to be numerous self-advocacy initiatives within services across the country who, are genuinely pushing for effective change for people with learning disabilities at local, national and European levels. However, some of these initiatives tend to be inconsistent due to a conflict of interest among service users and staff and also issues regarding funding.

Gray and Jackson (2002) indicates that self-advocacy can be either individual or in a group. Both forms are considered to be effective but self-advocacy groups tend to be the salient part of self-advocacy.

The Goodbody report (2004) Vol.1, emphasises that anyone can be an effective self-advocate provided they have the adequate advice, information and support. Similarly, Swain et al (2003) indicates that self-advocacy groups work collectively to create effective change in terms of social inclusion as well as supporting each other in the process. “Self-advocacy is an important engine for equality and participation.”¹⁰

There is evidence therefore, that self-advocacy tends to be the preferred form of advocacy for people with learning disabilities. Nevertheless, Atkinson argues that citizen advocacy has been the more influential form of advocacy. However, the Goodbody report (2004) Vol.1. and Lishman (2005) disagree as

⁹ Lishman (1997) pg. 278

¹⁰ Lundstrom (2008) pg. 3

they believe that self-advocacy has been the more influential type of advocacy, especially for people with learning disabilities.

1.2.2 Group advocacy:

Group advocacy evolved from self-advocacy. The group usually have a person who 'stands beside' or 'stands behind', depending on the group's requirements. The Goodbody report (2004) Vol. 1, indicates that group advocacy is an important form of advocacy that has the potential to move self-advocacy to higher level. The group have the opportunity to speak up on issues collectively as it gives individuals in the group a greater level of confidence to fulfil their full potential. Birmingham (2001) reiterates this point, but she also emphasises the importance of ensuring that there is an adequate level of support in order to fulfil the actions of the group. For example, it can include arranging an accessible meeting venue, transport, support from PA's (Personal Assistants) and staff within services. The participants for this research reiterate this point, as they believe that there tends to be a lack of support to attend group meetings. It appears that group advocacy overlaps with self-advocacy.

1.2.3 Citizen advocacy:

Citizen advocacy involves an unpaid volunteer working in partnership with a person with a learning disability for as long as the individual needs the support. Gray and Jackson (2002) emphasise that this service should be completely independent from service providers as there tends to be a conflict of interest persisting among many service providers. In other words, with reference to Stones model, previously mentioned, the advocate 'stands beside' the person whom they are supporting.

Volunteers are selected carefully through an extensive recruitment and training process. Anybody in the community can volunteer but they must provide references and apply for a Garda Clearance as part of the vetting procedure. Giles (1997) indicates that citizen advocacy schemes have been

in operation in the USA, Canada, Scandinavia, and the UK for a considerable period of time. For example, the Torfae Citizen Advocacy project established in Wales in 1989. Yet, it is a new type of advocacy in operation in Ireland. These schemes employ a coordinator to recruit and train volunteers before matching them up with a suitable partner. Tufail and Lyon (2007) stress the importance of recruiting and training volunteers, as it is vital that all volunteers clearly understand what their role entails. For example, the National Disability Authority (NDA) believes that the sole role of the advocate is to enable the person to “get their views across.”¹¹ Similarly, Flynn (2009) stipulates that advocates must understand and respond appropriately to the person’s wishes in order to enable the person to speak up.

It is vital for the advocate to “build up a trustworthy relationship with a person who is at risk of social exclusion and choose one or more ways to understand, respond and represent the person’s interests.”¹² Gray and Jackson (2002) strongly agree with this point, as citizen advocates are valued greatly in providing a means of support on a voluntary basis to enable people with learning disabilities to have their voices heard.

Another variation of this form of advocacy has been normalisation theory, which was established in Scandinavia in the 1960’s. This aims to address the inequalities faced by many people with learning disabilities at an international level. Similarly, as discussed by Gray and Jackson (2002), the Swedish interpretation of this theory is to ensure that people with learning disabilities must have the same “patterns of life and conditions of every day living as close as possible to the regular circumstances and ways of life as society.”¹³ In other words, the Swedish interpretation implies that people with learning disabilities must be treated as equal citizens in society. Goodley (2000) is in support of this theory, as he believes that it can be an effective form of empowerment for people with learning disabilities, as it ensures that these people are treated on an equal par with others in society as much as

¹¹ NDA (2000) pg. 11

¹² O’Brien (1987) pg. 3

¹³ Nirje (1998) pg. 33. cited in Gray and Jackson (2002) pg. 26

possible. On the other hand, Goodley suggests that this theory may also pose some risks in terms of service provision as the issue of conflict of interest between staff and people who avail of the services tends to arise frequently. Gray and Jackson note that normalisation has been renamed in the 1980's due to the North American interpretation meaning it is now known as social role valorisation. The theory now focuses on the social roles of people with learning disabilities in such a way that they are treated as equal citizens in society. This is an effective theory for citizen advocates to apply as they assist people with learning disabilities speak up in relation to the issues that affects their lives on a daily basis in society.

1.3 Representative advocacy

1.3.1 *Peer advocacy:*

Flynn (2009) indicates that peer advocacy is similar to citizen advocacy to a certain extent. A citizen advocate is a person without a disability representing or assisting a person with a disability. On the other hand, a peer advocate is a person who has a disability and who supports another person with a disability in a similar situation. A peer advocate is, often a person who is also a self-advocate. However, Grant et al (2005) criticises that the peer advocate does not always go through the same experiences, especially if the other person has a different disability. He points out that peer advocates need to accept that change may not happen overnight.

On the other hand, Gray and Jackson (2002) believe this plays a pivotal role for an individual availing of this type of advocacy, as the advocate has a greater level of knowledge relating to the relevant systems and organisations in order to enable the person to access their basic rights and entitlements. Birmingham (2001) indicates that "power dynamics" tend to be distributed at an equal level as both parties have experienced the same struggles and situations.¹⁴ "It aims to empower those who are powerless."¹⁵

¹⁴ Birmingham (2001) pg. 17

Empowerment is one of the principles that will be discussed below. However, family advocacy can often disempower people with a learning disability, as discussed below.

1.3.2. Family advocacy:

Flynn (2009) indicates that family members can also act as a representative advocate for their children or siblings in order to fight for their rights and entitlements. However, there tends to be a conflict of interest between the advocate and the person whom they are advocating for, as the advocate focuses on the person's 'best interest' rather than the person's needs and wishes. Nevertheless, Birmingham (2001) indicates this form of advocacy is considered to be quite effective in some regard, but the Goodbody report (2004) Vol. 1 believe that it has its potential to raise conflicts of interest between family members and the individual. For example, the family member may not allow the person to be more independent whereas the person wants to be more independent. Furthermore, P3 states "decisions have always been made about what is for their own good and what is in their own best interest and their own safety."

1.3.3 Legal advocacy:

A legal advocate is a person who is familiar with applying the legislation in terms of accessing rights for people with disabilities. In other words, legal advocates assist people to exercise or defend their rights.¹⁶

The Goodbody report (2004) Vol. 1 indicates that legal advocacy has been in operation in many countries such as Australia and North America. It has been in operation in Ireland also in terms of lawyers acting on behalf of a person with a disability in court. However, Weafer (2003) highlights that legal advocacy has played a significant role in the area of mental health.

¹⁵ Atkinson (1999) pg. 6

¹⁶ One for Us: <http://www.oneforus.com/Advocacy.32.0.html>.

1.4 Principles:

1. Empowerment
2. Autonomy
3. Inclusion
4. Citizenship

As discussed, there are many types of advocacy. Each varies slightly in their origins, use and values. Despite their differences Atkinson (1999) emphasises that the salient point of advocacy are the four main principles we are about to discuss. These principles remain the same no matter what type of advocacy is used.

1.4.1. *Empowerment:*

"The failure to empower is not something that will be tolerated in the 21st century. Disabled people all over the world are struggling to confront the process that excludes and segregates them and to escape from the institutions that are part of that." ¹⁷ The Goodbody report (2004) Vol. 1 echoes this point by stating that empowerment is considered to be the most salient principle of advocacy as it supports the other three principles about to be discussed. This emphasises the importance of empowerment for people with learning disabilities.

On the other hand, Grant et al (2005) indicates that empowerment is a process of power, but it is not given to people with a learning disability. This point is echoed in the People Connect report compiled by the Community and Participation and Inclusion Sub-Committee within the National Federation of Voluntary Bodies. This committee consists of people with learning disabilities and staff from various learning disability organisations throughout Ireland. The sub-committee held a consultation day for people with learning disabilities to identify the common barriers of social exclusion, which disempower these

¹⁷ Oliver (1996) pg. 93, cited in Ramcharan et al (1997) pg. xi

people from participating in the community. They found that the main barriers consist of the following:

- Accessible information
- Advocacy
- Attitudes
- Choice
- Disability Allowance
- Friendship
- Independence
- Support
- Transport

Gray and Jackson (2002) believe that involving people with learning disabilities in research has proven to increase their level of empowerment. This empowerment is evident from one participant's response:

"When they [people with learning disabilities] do research they want to bring it one step further, they want to bring it to the people who make changes. Rather than it being a tokenistic style of engagement, they want to go all the way with it." P4

1.4.2. Autonomy:

Autonomy "enables people to be more in control of their own lives, by having, support to make their views known and greater involvement in decisions"¹⁸. Grant et al (2005) believe that this is not always the case for many people with learning disabilities, as they are not listened to. However, autonomy is one of the main principles reiterated in the UN Convention on the Rights of Persons with Disabilities.

It is pivotal for us not to confuse autonomy with independence as autonomy refers to people directing their own lives in the way they wish to live it whereas independence means that you are not controlled by any else. As the Goodbody report clearly indicates that, in order to do this it is important for

¹⁸ Lochaber, cited in Atkinson (1999) pg. 16

advocates to provide the necessary support and advice to enable individuals to remain in control of their lives.

1.4.3. Inclusion:

Inclusion involves “welcoming people into groups and communities, on the basis of equality of opportunity and access.”¹⁹

It is crucial to ensure that people with disabilities are included in the process of advocacy in order to enhance the quality of life for people with disabilities. The Goodbody report (2004) Vol. 1 identifies many barriers to inclusion such as access to public transport and public buildings etc. In order to overcome this problem it is crucial for advocates to communicate and work collectively with professionals and people with learning disabilities.

1.4.4. Citizenship:

Advocacy is the key to protect the rights and privileges of all citizens in society. The Goodbody report (2004) Vol. 1 indicates that there are many barriers of exclusion and isolation that results in people with learning disabilities having their rights and privileges infringed. Similarly, Quin and Redmond (2003) indicate that the ideology of citizenship is an important point pertaining to any marginalised group, in this case disabilities. Gray and Jackson criticise that people with learning disabilities have experienced an unlawful amount of exclusion in society in the following ways:

- Segregation i.e. people with learning disabilities have been living in an institution for many years.
- Social exclusion
- Choices denied
- Very little opportunities made available
- Negative attitudes

¹⁹ Lee-Foster and Moorehead (1996), cited in Atkinson (1999) pg. 12

The above literature proves that many people with learning disabilities are not treated as equal citizens, which is unacceptable. Due to this fact, it is imperative that all advocates are aware of the importance of applying these principles to ensure that people with learning disabilities are given more opportunities to participate in the social life of the community and be heard.

1.5 Conclusion:

This chapter identified and discussed the types and principles of advocacy. This chapter also looked at the difference between the two components of advocacy; self-advocacy and representative advocacy.

The salient point in this chapter appears to be that self-advocacy is the preferred form of advocacy for people with learning disabilities both nationally and internationally. However, there is scope and room for other forms of advocacy such as public policy advocacy etc. The main principles of advocacy are crucial for advocates to apply in order for the process of advocacy to be effective.

The next chapter will examine the establishment of advocacy at an international level and how it eventually came to Ireland. In order to do this we will discuss the independent living movement, disability rights movement and the UN Convention on the Rights of Persons with disabilities. This will provide a clearer picture of the establishment of advocacy at an international level, which started in the USA, then spread to Europe before it eventually came to Ireland.

Chapter 2:

The Development of Advocacy from an international level to a national level

2 Introduction:

This chapter will examine the development of advocacy from an international level to a national level.

Firstly, this chapter will discuss the establishment of the independent living movement and how advocacy has derived from this movement by discussing by firstly discussing the international perspective and secondly the national perspective.

Secondly, this chapter will discuss the disability rights movement by focusing on the following:

1. The enhancement of rights for people with learning disabilities.
2. The paradigm shift from the medical model to the social model of disability.
3. The contribution of self-advocacy and citizen advocacy to the movement.

Finally, this chapter will outline the effects of international legislation on the development of advocacy in general. This section will then discuss the salience of the recent UN Convention on the Rights of Persons with Disabilities on shaping future directions of advocacy.

2.1 Independent Living movement:

2.1.1 *International Perspective:*

The concept of independent living initially originated in the 1970's in the USA. Morris (1993) indicates that in 1973, three students with a physical disability

had the opportunity to attend university in Berkeley based in California with the aid of their Personal Assistants (PA's). Morris stressed how this opportunity has empowered these individuals to a great extent. When these students graduated from university, they were inspired to set up the world's first ever Centre for Independent Living (CIL) in Berkeley. Their aim was to enhance the quality of life for people with learning disabilities²⁰ by providing assistance to empower these people to take control of their own lives, with the necessary assistance required. For example, adequate advocacy services, accessible transport etc. The CIL Carmichael House Strategic Plan 2009 – 2014 states that within a space of ten years, two hundred CIL's were established across the United States. This was the beginning of the independent living movement

Meanwhile, Fleischer and Zames (2001) indicates that the development of the independent living movement has provided a greater prospect for people with learning disabilities to enable them to live more independently in the community rather than living in an institution. On the other hand, Gray and Jackson (2002) agree with the positive effects of the independent living movement, but people with learning disabilities still tend to be regarded as the most vulnerable group among the disability sector regardless of this movement. Therefore, Tufail and Lyon (2007) emphasise that life is about advocating by making choices and speaking up, but people with learning disabilities are not always given this opportunity. The UK Governments White Paper, *Valuing People* indicates that people with learning disabilities should be treated on equal par as all citizens in society. This report refers to people with learning disabilities as follows:

“People with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do. Learning disability includes the presence of:

²⁰ Morris (1993) refers to all people with disabilities but in this case we are focusing solely on people with learning disabilities.

- A significantly reduced ability to understand new or complex information (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning)”²¹

Gray and Jackson believe that these characteristics listed above tends to be the reason why many people in society have attitude problems towards people with learning disabilities which in turn proves why they are the most vulnerable group in society. Similarly, the Goodbody report (2004) Vol.2 also discovered that people with learning disabilities tend to be the most vulnerable group of disabilities. Meanwhile, the countries discussed in this report aim to “ensure full participation and equality in life for those with disabilities.”²²

At this point, it is crucial to consider the significance of independent living for people with learning disabilities. The European Network for Independent Living (ENIL) put forward a concise definition, which consists of the following:

“Independent living means equal independence, equal rights, equal respect and the right to the same self- determination, control and choice as non-disabled people. Independent living is a philosophy empowering individuals to achieve an equality of opportunity and participation.”²³

Article 19 of the UN Convention on the Rights of Person with Disabilities reiterates the key points identified in this definition. People with learning disabilities place a legal right in legislation for people to live independently in the community despite of their disability. The (ECCL) European Coalition Community Living (2008) emphasise that advocacy is a key tool in the independent living movement. “Advocacy is about improving the lives of people with disabilities and ensures that they are able to live independently.”²⁴ On the other hand, Tufail and Lyon (2007) agree with the ECCL, but they indicate how difficult it can be for some people with learning disabilities to

²¹ Valuing people (2001) UK Dept. Health: A White Paper pg. 14.

²² Goodbody Economic Consultants Vol. 2. pg. 73.

²³ European Network for Independent Living (ENIL): www.enil.eu

²⁴ ECCL (2008) pg. 13.

speak up for themselves as they do not have the courage or the skill to speak up. But, with the relevant support from an advocate this can change.

The philosophy of the independent living movement is based on four assumptions put forward by Morris (1993). These assumptions consist of the following:

1. "All human life is of equal value.
2. Anyone, whatever their impairment, is capable of exercising their choices.
3. People who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives.
4. Disabled people have the right to participate fully in society."²⁵

Morris (1993) discovered that people with physical and sensory disabilities have been more active in the independent living movement more so than people with learning disabilities as they are not encouraged to speak up for themselves as much as other people with disabilities. By looking at these four assumptions, it is evident that the independent living movement was established to empower all people with disabilities to live independent lives. In other words, people with learning disabilities should be participating at an equal level as those with physical and sensory disabilities. On the other hand, Grant et al (2005) indicates that these assumptions also promote advocacy within the movement, but for the majority of people with learning disabilities who have predominantly found it difficult to get their voices heard have been problematic. It appears that the importance of advocacy is a very important tool that needs to be considered for many people with learning disabilities throughout the world.

The ENIL²⁶ indicate that since the establishment of the independent living movement in the 1970's in the USA, the idea of independent living spread to

²⁵ Morris (1993) pg. 21.

²⁶ European Network Independent Living: www.enil.org

Europe in the late 1970's, which encouraged many people to move out of institutions and live independently in the community. The ENIL was established in April 1989 at a conference held in Strasbourg where approximately two people with a disability from the conference set up this European network. However, the Independent Living Institute stress that independent living does not mean that "we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled"²⁷ citizens enjoy.

Three years later, the independent living movement eventually came to Ireland as discussed below.

2.1.2 National Perspective:

The Carmichael House Strategic Plan 2009 - 2014 states that the establishment of the first CIL was in Carmichael House, Dublin in 1992 which is a grassroots organisation. This first CIL was established by a group of people with disabilities, which strengthens the movement even further as this is how the movement was initially established. There is now 24 CIL's nation wide, which strives to develop the paradigm shift from the medical model to the social model of disability, which will be discussed below. Furthermore, Quin and Redmond (2003) indicates that the manifestation of the independent living movement in Ireland saw the establishment of the Irish (CIL's) during the early 1990's, along with the formation of a small number of disability organisations since 2000 such as the Forum of People with Disabilities²⁸ and People with Disabilities Ireland (PwDI) which is a cross-disability organisations advocating for all people with disabilities.

It appears that there tends to be a number of people with disabilities working at grassroots level demanding their rights and entitlements as equal citizens. However, this tends to be a minority group of people, as the participants for this research have proven that people with learning disabilities do not get this

²⁷ Independent Living Institute: www.independentliving.org

²⁸ This organisation no longer exists at this point in time.

opportunity to speak up and demand their rights and entitlements in comparison to people with physical or sensory disabilities. For example P1 stated:

“Most of the people I work with spent a large proportion of their lives in institutions. They have grown accustomed to having no choice in their lives and having all their decisions made for them.”

Similarly, Quin and Redmond (2003) criticises that the independent living movement tends to only involve people with significant physical disabilities, even though it is supposed to be an inclusive movement for all people with disabilities to promote a greater level of independence.

Having discussed the independent living movement at an international and a national level, it appears that the movement does not deal with advocacy directly but it does in an indirect manner, as it aims to empower all people with disabilities to live independently and take control of their own lives with the necessary support. Nevertheless, Carmichael House promotes advocacy in their work in developing the CIL's here in Ireland. This is evident in their Strategic Plan, as advocacy is one of their core goals. This Strategic Plan emphasises that advocacy is a core part of the work carried out by the CIL's throughout the country. This is also evident in their mission statement below:

“Our purpose is to empower and enable people with disabilities to achieve independent living as a human right. We will strive to ensure that people with disabilities can actively participate as equal citizens, with the choices, control and responsibilities that this implies through action research, support and advocacy.”²⁹

However, a recent CIL Network Council meeting took place in Galway on 11th May 2009, which was a national meeting for all the members (people with disabilities) of CIL's throughout the country. The most salient points that were stressed by the members from the Galway branch of CIL were the lack of service provision such as the PA service and the accessible transport service

²⁹ Carmichael House CIL: www.dublincil.org/

as well as the lack of consultation and communication with the members. Of particular significance, the speakers spoke about providing an advocacy service to empower the members to live independently by availing of the PA service and accessible transport from their local CIL. However, another point raised by the members was that these services are insufficient which in turn disempower people with disabilities rather than empower them.

The next section will discuss the development of advocacy through the disability rights movement.

2.2 Disability Rights Movement:

Grant et al (2005) indicates that the disability rights movement was initiated in the USA after the independent living movement, previously discussed. The independent living movement contributes greatly to the disability rights movement in providing people with learning disabilities the right to live independently in their own community. Hence, the Goodbody report (2004) Vol. 2 highlights that this movement has enhanced the prospects for people with learning disabilities to a certain extent, with the enactment of various pieces of legislation and other models such as the UN Convention on the Rights of Persons with Disabilities and the paradigm shift from the medical model to the social model of disability, due to be discussed below.

On the other hand, the Council of Europe Disability Action Plan 2006 – 2015 indicate that, even though this movement has a positive effect for people with disabilities, there still tends to be many people with learning disabilities who are not active in this movement due to a lack of awareness regarding learning disability. This action plan proposes that a lot of work needs to be done pertaining to awareness training in order for people without a disability to “see disabled people as equal citizens and as people who have the same rights.”³⁰ This plan also stresses that having laws and supports in place is not enough

³⁰ Council of Europe Action Plan 2006 – 2015 pg. 26.

but rather that, everyone needs to work together to highlight awareness regarding all types of disability.

2.2.1. Rights for people with learning disabilities:

Gray and Jackson (2002) stress that human rights for people with learning disabilities is a crucial point of any advocacy service as they are entitled to speak up about their rights and entitlements regardless of how mild or severe their disability may be. Similarly, Flynn (February 2009) argues that people with learning disabilities do not always understand their rights and entitlements which suggests that the support of an advocate is essential to enable these people to take control of their own lives and be more active in this movement.

Stone (1999) indicates that people with learning disabilities have been regarded as people without power, rights and value for too long. Therefore, Gray and Jackson (2002) welcomes the self-advocacy movement throughout England, which will be discussed in section 2.3 of this chapter, as it gives people with learning disabilities equal power, rights and values as everyone else. Gray and Jackson also indicate that citizen advocacy and self-advocacy, previously discussed in section 2.1 and 2.3 of chapter 1 prominent types of advocacy used in the learning disability area.

Even though research has shown that people with learning disabilities are more vulnerable in comparison to people with physical or sensory disabilities, it appears that the disability rights movement has enhanced the rights for people with learning disabilities through the process of advocacy. This can also be seen in chapter one and it will become more evident as we now discuss the paradigm shift from the medical model to the social model of disability.

2.2.2. Paradigm shift from the medical model to the social model of disability:

Under the medical model of disability, Council of Europe Action Plan 2006 – 2015 indicates that people with disabilities were seen as patients who needed care, which is known as the medical model. Whereas the social model states that people with disabilities have been disabled by society and that, they should be included in society as equal citizens. Therefore, the Goodbody report (2004) Vol.2 highlights that the medical model does not acknowledge the need for advocacy whereas the social model recognises the need for advocacy to enable people with learning disabilities to participate in society with the necessary supports from an advocate when required. Furthermore, Goodley (2000) indicates that the shift from the medical model to the social model has brought about rapid change, which is evident from the self-advocacy movement. On the other hand, Stone (1999) notes that there is a considerable amount of people with learning disabilities who “are denied their right to inclusion.”³¹

The Carmichael House Strategic Plan states that prior to the independent living movement, as discussed in section 1 of this chapter, the predominant understanding of disability initially came from the medical model of disability. However, the plan emphasises that the independent living philosophy, promotes a social model of disability, which enhances the inclusion of all people with disabilities. On the other hand, Qinn (2005) stresses that the current reality tends to be that “people are treated as objects and not as subjects throughout the world. It is this ‘objectivisation’ of the human spirit that demeans us all.” This point stated by Quinn is a valid point as it tends to be reiterated in the literature discussed in this dissertation.

Morris (1993) believes that the disability rights movement has enhanced the paradigm shift towards people with learning disabilities to a certain extent but there still tends to be many ambiguities that still exist throughout the world.

³¹ Stone, (1999) pg. 18.

For example, P5 states that “people are not given the opportunity to speak up and some people do not know how to access information relating to their rights and entitlements.” On the other hand, Russel (2000) indicates that the medical model of disability is still pervasive, as many people’s disabilities are still perceived as being medical matters to a certain extent across the globe. It appears that there are many arguments for and against the shift from the medical model to the social model but there is a strong potential to improve this shift for people with learning disabilities by applying the types and principles discussed in chapter 1.

2.2.3. Self-advocacy and citizens advocacy:

Gray and Jackson (2002) indicate that self-advocacy and citizens advocacy tend to be the types of advocacy used the most among people with learning disabilities. Citizen advocacy originated from the normalisation theory, now known as the social role valorisation theory whereas self-advocacy originated from the disability rights movement and the social model of disability.

Morehead (1996) cited in Gray and Jackson (2002) indicates that the self-advocacy movement emerged in Sweden, and then in the USA in the 1960’s. The self-advocacy movement did not officially take off until the establishment of Peoples First in 1984. However, the (PwDI) People with Disabilities Ireland report (2001) indicate that self-advocacy emerged in Ireland in the 1990’s within service providers such as the Brothers of Charity before independent advocacy services began to develop from 2000 onwards.

Goodley (2000) indicates that self-advocacy and citizen advocacy has contributed greatly to the disability rights movement. Similarly, the Goodbody report (2004) Vol. 2 emphasise that there are various citizen advocacy schemes working effectively in Australia, Sweden, the USA and the UK, but there are many challenges such as funding. Also, Gray and Jackson (2002) highlights that the self-advocacy organisations in the UK have carried out extensive work by developing self-advocacy groups throughout the country. However, Dowse indicates that self-advocacy poses many challenges such as

conflicts regarding its “nature, direction and strategy.”³² Similarly, Ramcharan (1997) believe that self-advocacy tends to be difficult for some people with a learning disability due to their level of understanding, but the support of an advocate can help to overcome this obstacle.

2.3. International Legislation:

Birmingham (2001) emphasise that all people with disabilities have the same rights and entitlements as all citizens in society. Meanwhile, Flynn (2008) indicates that in recent years, disability rights are now being taken into account at an international level in order to ensure that their rights are set in legislation such as the convention specifically for women and children. However, Swain et al (2003) states that disability rights are not explicitly mentioned in the UN’s legal instruments or in the European Convention on Human Rights. Due to this need, the UN has recently developed the Convention on the Rights of Persons with Disabilities, which will be discussed below. The UN Convention is regarded as having the potential to promote basic rights and entitlements, which will encourage the development of advocacy in Ireland for people with learning disabilities.

Similarly, the American with Disabilities Act (1990) has influenced Ireland’s development on policies and procedures over the past number of years, as indicated by the Centre of Disability, Law and Policy Strategic Plan 2008 - 2012 influenced the disability rights movement to a great extent.

2.3.1. *UN Convention on the Rights of Persons with Disabilities 2006*

Article 24 of the Convention indicates that the UN General Assembly officially adopted the UN Convention on the Rights of Persons with Disabilities on 13th December 2006, and it opened for signature on the 30th March 2007 at the UN Headquarters in New York. Lindquist (2008) indicates that the ratification of the Convention will provide a powerful incentive for people with learning

³² Dowse (2001) pg. 132.

disabilities to fight for their rights and entitlements with the support of an advocate. Similarly, Degener, cited in Blank (2005) believes that the law reforms in the area of disability such as this convention, intends to decrease the level or perhaps demolish segregation, institutionalisation, exclusion and it aims to provide equal opportunities for all people with disabilities.

On the other hand, the Carmichael House Strategic Plan believe that this Convention would be a powerful tool in enhancing the right for people with disabilities to live independently (Article 19), but it criticises that it does not cover advocacy directly and the plan expresses its disappointment that it is not yet ratified in Ireland.

Meanwhile, O'Brien (2008) states in an Irish Times article that the International Service Ireland (ISI) urges the Irish government to ratify the convention as it is imperative to strengthen the rights for people with disabilities in Ireland and abroad. However, the convention consists of 50 articles in total. Some of the core sections and articles that relate to advocacy consist of the following:

- “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence. Article 3(a)
- Full and effective participation and inclusion in society. Article 3(c)
- Access to justice. Article 13
- Living independently and being included in the community. Article 19
- Freedom of expression and opinion and access to information. Article 21”³³

It appears that the convention has a strong potential to enhance the development of advocacy for people with learning disabilities in Ireland and abroad.

³³ UN Convention on the Rights of Persons with Disabilities

2.4 Conclusion:

This chapter discussed the development of advocacy by exploring the establishment of the independent living movement from both an international and a national perspective, the disability rights movement and the effects of international legislation such as the recent disability convention.

It evident from this chapter that the independent living movement, disability rights movement and the disability rights convention contributes greatly to the development of advocacy at an international and a national level. However, the main flaw that derives from this chapter tends to be that people with learning disabilities are not as active in comparison to people with physical or sensory disabilities. This indicates that advocacy is an important support for people with learning disabilities.

The next chapter will discuss the development of advocacy in Ireland through the establishment of the Citizens Information Board.

Chapter 3:

The current situation of Advocacy in Ireland

3 Introduction:

This chapter will discuss the development of advocacy in Ireland since the establishment of the Citizens Information Board (CIB) in 2000, which was formerly known as Comhairle.

Firstly, this chapter will discuss the general background regarding the Citizens Information Board's commitment to developing advocacy in Ireland for people with disabilities by identifying and discussing the three main strands, recommended by the Goodbody report (2004) Vol. 1, by which the CIB intends to develop advocacy services.

Secondly, this chapter will identify and discuss the contribution towards the development of advocacy from various disability organisations since the establishment of Comhairle (CIB) in 2000.

Thirdly, this chapter will discuss some of the best practice guidelines to assist advocates in improving the quality of advocacy services for people with learning disabilities.

Finally, this chapter will briefly discuss the impact of the current economic crisis over the past year, pertaining to the development of advocacy by discuss the impact of the recent McCarthy report with regards to funding for advocacy provisions.

3.1 The development of advocacy through the CIB:

The emergence of advocacy came to light due to the initial establishment of Comhairle (CIB), which was based on the Comhairle Act 2000. Flynn (2007)

highlights that Comhairle (CIB) is the sole organisation that is responsible for developing and promoting advocacy for people with disabilities in Ireland. Meanwhile, P8 indicates that prior to the Comhairle Act 2000, it was known as the National Social Services Board (NSSB). The Strategy for Equality published in 1996 recommended that the National Rehabilitation Board (NRB) and the NSSB should amalgamate together which is how Comhairle was initially formed. On the other hand, Weafer (2003) indicates that advocacy has not been a prominent feature in Ireland before the establishment of Comhairle. With the exception of some service providers, where self-advocacy and citizen advocacy has been in operation since the late 1990's such as the Brothers of Charity.

Comhairle's main remit is to develop advocacy services for people with disabilities.³⁴ The main functions reiterated in the Comhairle Act 2000 consist of the following:

- "To ensure that individuals have access to accurate, comprehensive and clear information relating to social services.
- To support the provision of, or directly provide, advocacy services for people with a disability."³⁵

Birmingham (2001) also reiterates these functions in her report. Furthermore, she believes that these functions are essential in order to develop better quality advocacy services for people with disabilities in Ireland. On the other hand, Weafer (2003) indicates that even though, Comhairle is undertaking tremendous work in developing advocacy provisions for people with disabilities, there still tends to be many people with learning disabilities who are denied access to their basic rights and entitlements. This may be due to some of the following barriers identified in the Regional Fora report (2002). These consist of the following:

³⁴ From this point we will refer to Comhairle (Citizens Information Board) as the CIB from this point on.

³⁵ Comhairle Act 2000. Section 7 (1).

- “Language/literacy and cultural impediments.
- The approach of state bureaucracies.
- Lack of statutory entitlements to some services.
- Social inequalities in society.”³⁶

Weafer (2003) also reiterates these barriers and believes that advocacy is a key tool to combat these inequalities for people with learning disabilities.

The Comhairle Newsletter (2004) 2(2) indicate that a new Comhairle (amendment) Bill 2004 was proposed to provide a “legal backing for a new advocacy remit for Comhairle.”³⁷ This Bill should also provide for the provision of the personal advocacy service, due to be discussed in the next section. However, the CIB *Advocacy Guidelines* (2007) highlights that the new Citizens Information Act 2007 was finally adopted to replace the Comhairle Act 2000. Meanwhile, P8 states that the replacement of the Comhairle Act was to legally change the name to the Citizens Information Board, as “the minister at the time did not like the name Comhairle.” The opening statement of the Citizens Information Act 2007 indicates that the Act “amends and extends its functions”³⁸ and also includes the provision for the personal advocacy service which will be discuss below.

However, Lunstrom (2008) has noted that this legislation is the only means of legislative responsibility put in place responsible for the development and implementation of advocacy initiatives in Ireland. Since the Comhairle Act was established, the CIB plays a crucial role in developing and implementing of independent advocacy services in the community and voluntary sector. This development appears to be evident in the Comhairle newsletters up to this point.

³⁶ Regional Fora report 2002 pg. 13

³⁷ Comhairle Newsletter 2(2) pg. 1

³⁸ Citizens Information Act 2007. Opening statement of Act pg. 3

3.1. 2. The three strands to develop advocacy services:

The three strands consist of the following:

- The programme for community and voluntary organisations.
- Personal Advocacy Service (PAS).
- Community Visitors Programme.

The CIB has funded 46 projects under the community and voluntary sector to date whereas the PAS and the 'community visitors programme' have not been rolled out due to current financial constraints. We will now discuss each one in turn.

3.1.3 *Community and Voluntary Programme:*

The Comhairle Newsletter (2004) 2(3) indicate that the community and voluntary programme was the only strand that has been implement to date. The Goodbody report (2004) Vol. 1 recommended that this should be the first strand to be implemented in order to establish advocacy projects in the community that should be completely independent from service providers. This initiative is regarded as a professional representative advocacy service provided by a trained person who has the skill to assist and represent people with disabilities in "working out their needs and options and representing them if necessary."³⁹ Furthermore, O'Callaghan (2009) states that the CIB "called for expressions of interest from organisations in the community and voluntary sector to develop advocacy services for people with disabilities" in 2005. However, many organisations responded to the CIB by applying for the funding to develop an advocacy service in their area, but only some of the organisations received the funding. For example, the Comhairle newsletters published in 2005 stated that they received 47 applications but only 13 received the funding. Meanwhile, Flynn (2007) indicates that the CIB have been allocated a specific amount of funding from the Department of Social

³⁹ Comhairle Newsletter 2(4) pg. 1

and Family Affairs to support these organisations but they must comply with the Advocacy Guidelines published in 2005 with a revised publication in 2007. Meanwhile, the Comhairle Newsletter (2009) 11 states that there are currently 46 advocacy projects in existence under this programme. Every six months the advocates from these projects compile a report regarding their progress for submission to the CIB. These reports outline the “sterling work being done” and the various challenges faced by advocates.⁴⁰ For instance, the challenge of dealing with long waiting lists of clients as there is an insufficient number of advocates in place to deal with people quickly and also a limited amount of time and resources is another recurring challenge reiterated in the reports. P3 believes there should be at least two advocates in each county in order to work through the waiting lists swiftly and also to reach more vulnerable people who are not getting access to advocacy services such as people with learning disabilities. However, P8 hoped that there would be new funding to bring the number of projects up to at least 50 or 60 but due to budget cuts this did not happen.

3.1.4 Personal Advocacy Service (PAS):

The Comhairle Newsletter (2004) 2(3) indicates that the aim of the PAS is to employ a professional advocate to deal with complex issues such as assisting people with disabilities in relation to making complaints, assessment of need and accessing relevant services. Similarly, section 5 of the Citizens Information Act 2007 emphasise that a personal advocate must have the relevant “qualifications, expertise and experience” to deal with complex cases.⁴¹ Meanwhile, Flynn (February 2009) indicates that the PAS is regarded as a last resort provided all the other advocacy options have been explored first.

However, the Goodbody report (2004) Vol. 1 recommended that the PAS should be implemented two years prior to the community and voluntary programme. Furthermore, Flynn (2007) states that the aim of this approach

⁴⁰ Comhairle Newsletter, Issue 11 pg. 1

⁴¹ Citizens Information Act 2007 section 5.

was to allow the voluntary organisations to identify the most vulnerable groups among the disability sector and identify the most urgent cases that the PAS should focus on once implemented. However, the Comhairle Newsletter 10 indicates that the PAS has been postponed until such a time when there will be sufficient funding in place in the near future. Three participants from this research, who are employed by the CIB, expressed their disappointment regarding the postponement of this service. These participants believe it would have been a great resource for people with learning disabilities, as they tend to need more support in comparison to people with physical and sensory disabilities.

3.1.5 Community Visitors Programme:

The Comhairle newsletters indicate that the purpose of the 'community visitors programme' is to provide an independent advocacy service for residents residing in residential institutions. Furthermore, this programme aims to "monitor the treatment of people with disabilities in institutions"⁴² as they tend to be the most vulnerable. The Goodbody report Vol. 1 sets out the main roles of an advocate under this programme. These consist of the following:

“Undertake regular visits to facilities.

Identify issues and problems from the perspective of the resident.

Respond to the requests of residents and look into complaints.

Identify and record problems of a systematic nature.

Refer cases to the PAS and the community and voluntary organisations, where action by the service provider is not forthcoming.”⁴³

However, P8 and P7 indicate that due to the recent budgetary cutbacks, this strand unfortunately has not been fully implemented. Nevertheless, P7 highlights that there are some advocates from the community and voluntary advocacy projects who work specifically with people in residential setting

⁴² Flynn, (February 2009) pg. 2.

⁴³ The Goodbody report (2004) Vol. 1 pg. 79.

3.2. Organisations contribution to advocacy:

These consist of the following:

National Disability Authority (NDA)
People with Disabilities Ireland (PwDI)
Inclusion Ireland
National Federation of Voluntary Bodies

3.2.1 *National Disability Authority (NDA):*

The PwDI report (2004) indicates that the CIB and the NDA were both established during 2000 under the Comhairle Act 2000 [CIB] and the National Disability Authority Act 1999 [NDA]. Both of these organisations have advocacy as their main remit. However, the CIB focuses on the provisions of advocacy services whereas the NDA focuses on developing policy pertaining to the development of advocacy in Ireland. Furthermore, the NDA has five core functions by which they aim to develop advocacy policies, which are reiterated in section 8 of the Act and also on their website. These consist of the following:

- “To act as a national body to assist in the coordination and development of disability policy.
- To undertake research and develop statistical information for the planning, delivery, and monitoring of programmes and services for people with disabilities.
- To advise the minister on standards for programmes and services and prepare codes of practice.
- To monitor and implement the standards and codes of practice.
- To take the lead in both encouraging and recognising the promotion of equality of people with disabilities.”⁴⁴

⁴⁴ National Disability Authority: www.nda.ie

Meanwhile, the NDA Strategic Plan 2007 – 2009 focuses solely on the monitoring and implementation of the National Disability Strategy, which was launched by the government 2004. This Strategic Plan aims to underpin the participation of people with disabilities in society. The National Disability Strategy includes advocacy as one of its four elements. On the hand, it is evident from reading the NDA’s strategic plan that people with disabilities are not being consulted regarding policy and practice. It appears that the NDA contributes to the development of advocacy in terms of lobbying government departments and conducting research pertaining to disability issues in Ireland.

3.2.2 People with Disabilities Ireland (PwDI):

PwDI is a cross disability organisation that promotes advocacy for all people with disabilities throughout the country. The PwDI’s first strategic plan 2003 –2006 sets out five priority areas in order to contribute to the development of advocacy. These consist of the following:

- “Lobbying.
- Communication.
- Training/Education/Employment.
- Research.
- Increasing its membership.”⁴⁵

These were the main areas that are reiterated by their members [people with disabilities] in this Strategic Plan. However, the PwDI report (2004) reflects the views and concerns from many of the PwDI members who attended the series of five seminars, which took place throughout the country. The seminars were characterised by the “vibrancy, interest, and motivation of the participants.” Nevertheless, according to the report there tends to be a lack of advocacy support from the organisation even though they aim to promote advocacy. The findings of this report emphasise that advocacy is an integral

⁴⁵ People with Disabilities Ireland: http://www.pwdi.ie/about_pwdi/index.htm

part of support necessary for all people with disabilities and not everyone has this support available to them.

3.2.3. Inclusion Ireland:

Inclusion Ireland was established in 1961, which was formally known as NAMHI, which has recently changed its name to Inclusion Ireland in order to promote inclusion for all people with learning disabilities.⁴⁶ The Inclusion Ireland Strategic Plan 2007 – 2012 reiterates that Inclusion Ireland is a national organisation that promotes the rights of people with learning disabilities throughout Ireland. This Strategic Plan was launched at the national AGM and conference held in April 2007 by Ms. Carroll, who is the CEO of Inclusion Ireland. At this conference Ms. Carroll stated that “advocacy is one of the key elements of the plan and Inclusion Ireland wants to deliver a top class advocacy service.” However, Ms Carroll recognises that advocacy is time consuming and can be costly. Nevertheless, Inclusion Ireland is fighting this challenge.

Meanwhile, Inclusion Ireland initiated a number of advocacy projects in 2002, which were implemented in 2003. These projects consist of the following:

- EDS (Enhancing Disability Services scheme) ‘Who decides and How?’ – An awareness campaign which commenced in 2005 regarding the issue of legal capacity and decision making.
- Walkinstown Association self-advocacy project – Inclusion Ireland delivered an advocacy course to staff and service users in the Association in 2005.
- Personal Advocacy Project – funded by the CIB in 2005.

⁴⁶ NAMHI (National Association of Mentally Handicapped in Ireland).

Inclusion Ireland state on their website that they have changed the name to Inclusion Ireland as the term is no longer used and it offends many people, especially self-advocates. Also, note that Inclusion Ireland use the term ‘intellectual disability’ in there literature but this dissertation is using the term ‘learning disabilities.’

- Independent advocacy project commenced in 2004 – run by Inclusion Ireland, HSE and the CIB to develop a model of best practice for advocates working with people with learning disabilities.
- Self-advocacy project: ‘My Voice, My Choice’ – commenced in 2003 with funding from the CIB.⁴⁷

It appears that Inclusion Ireland is contributing greatly to the development of advocacy for people with learning disabilities despite the challenges regarding lack of resources due to the current funding cutbacks.

3.2.4 National Federation of Voluntary Bodies:

The National Federation of Voluntary Bodies is a national umbrella organisation, which consists of 62 member organisations that provide direct services and supports to people with learning disabilities. The Federation aims to “promote the equalisation of opportunity” for people with learning disabilities through the “provision of high quality, person centred services.”⁴⁸ One of the participants, P4 stated that this overall aim is achieved in the following ways:

Developing policies and research in consultation with its member organisations and people with learning disabilities.

Dissemination of information.

Supporting people with learning disabilities to conduct their own research.

In order to put these points into action the Federation has a number of sub committees by which research is developed with the inclusion of people with learning disabilities. P4 listed these sub committees as follows:

Research sub committee.

Training sub committee.

⁴⁷ A list of Inclusion Irelands advocacy projects: <http://www.inclusionireland.ie/projects.asp>

⁴⁸ National Federation of Voluntary Bodies Introduction: <http://www.fedvol.ie/Introduction/Default.758.html>

Community participation and inclusion sub committee – this committee compiled a report identify the barriers and solutions to community and participation and inclusion as discussed in chapter one.

Quality service sub committee.

It appears that the Federation are contributing to the development of advocacy in terms providing people with learning disabilities the opportunity to be involved in various research projects.

3.3. Best practice Guidelines for advocates:

The Comhairle newsletters emphasise the salience of best practice models to enhance the quality of advocacy services for people with learning disabilities. Therefore, the CIB developed advocacy guidelines to assist advocates in the community and voluntary sector in 2005 in collaboration with the Goodbody Consultants. These guidelines have been revised in 2007 in light of the development of advocacy projects since 2005. Nevertheless, it is important to note that these guidelines are essential for any advocate whether they are involved in a CIB advocacy project or not.

CIB Advocacy Guidelines (2007) identifies some key principles for both individual advocates and organisations to take note of. These consist of the following:

Individual advocates:

- Empower the person with a disability where possible;
- Respect the person's wishes;
- Take into account the persons best interests;
- Acting independently;
- Maintaining confidentiality;
- Acting with diligence and competence.

Organisations:

- The project must have a clear purpose and specific target group;

Ensure equal access;

The project must be independent and the potential to reduce conflict of interest;

Advocates must be trained, supported and supervised to agreed standards;

Confidentiality and data protection policies must be developed.

However, while Browne et al (2007) agrees with these principles, they point out that there tends to be a lack of support in terms of supervision for advocates. Meanwhile, Browne recommends that there should be a panel of experts available to support advocates when they are dealing with complex issues that may have a personal effect on the advocate or they may just need advise on the best options to deal with the situation such as conflict between service providers or family members.

A significant development in the area of education and training for advocates was the launch of a new advocacy course, established by the Equality Authority and the CIB in collaboration with the Sligo IT. The Comhairle Newsletter

2(3) indicates that the title of the course is the 'Higher Certificate in Advocacy studies.' It is a distance-learning course over a period of two years. On the one hand, Browne et al (2007) states that this course offers a great deal of knowledge, but on the other, argues that "it's not until you go out there that you get to know what you are really doing."⁴⁹ Now we will discuss briefly the impact of the current economic crisis on the development of advocacy provisions.

3.4. Impact of the current economic crisis on Advocacy Provision:

The Disability Federation of Ireland (DFI) Newsletter (August 2009) indicates that the current economic downturn has a significant impact on the development of advocacy provision in Ireland to a great extent. Similarly,

⁴⁹ Browne et al (2007) pg. 24.

some of the participants in this research have expressed their disappointment with the postponement of the PAS and the community visitors programme previously discussed. On the other hand, the development of the community and voluntary sector advocacy projects contributed greatly to the development of advocacy.

Meanwhile, the recent McCarthy report proposes some drastic cuts in terms of disability funding in the areas of health, social welfare, education etc. The DFI newsletter (August 2009) urges the government to make fair and equitable decisions regarding this funding, as it will have an effect on the lives of all people with learning disabilities.

3.5. Conclusion:

This chapter discussed the development of advocacy in Ireland since the establishment of the CIB in 2000. Firstly, we discussed the emergence of advocacy through the establishment of the CIB, which has enhanced the development of advocacy to a large extent. Next we identified and discussed the three strands by which the CIB intends to develop advocacy in Ireland. However, only one of these strands has actually been implemented. Secondly, this chapter discussed the contribution of various disability organisations towards the development of advocacy. Thirdly, this chapter identified a number of important guidelines for individual advocates and organisations in order to enhance the quality of advocacy services. Finally, this chapter briefly discussed the impact the current economic crisis on the development of advocacy.

It is evident that the development of advocacy in Ireland has contributed greatly to the lives of many people with disabilities, but there still tends to be many people with learning disabilities who are not involved in the process of advocacy. This will be evident in the next chapters when we identify the common challenges of advocacy for people with learning disabilities.

Chapter 4:

Overall findings of this Research

4. Introduction

This chapter will present the overall findings of this research identified by the participants involved. We will identify the common questions posed to all participants followed by a brief discussion and a sample of their responses.

The aim of this research project was to investigate the concepts and challenges of advocacy from the perspective of people with learning disabilities and also the necessary actions required to enhance advocacy services.

This research involved asking a number of questions that were put to all participants. These consist of the following:

1. What is advocacy and what are the main purposes of advocacy?
2. What are the common challenges of accessing advocacy services from the viewpoint of a person with learning disability?
3. What are the necessary actions required to enhance advocacy services for people with learning disabilities?

[Refer to appendix for further questions]

4.1 What is advocacy and what are the main purposes of advocacy?

This is a deceptively simple question, but yet it was important to ask in order to highlight this relatively new concept. It is apparent from the literature and the responses from participants that term 'advocacy' tends to be a broad spectrum. However, the participants stressed that the main definition of advocacy is to empower people to speak up for themselves or others and everyone should be listened to on an equal basis. Furthermore, the main

purpose of advocacy tends to be the importance of enhancing the quality of life for people with learning disabilities and to be treated as equal citizens in the community. Some of the responses pertaining to this question consist of the following:

- “Advocacy is about listening to what people have to say and speaking up about issues that affect their lives. The purpose of advocacy allows us to live independent lives.” P6
- “Advocacy is all about empowering the person and the purpose of advocacy is to empower people by addressing inequality.” P3
- “Advocacy is about speaking up to get access to your rights and entitlements. The purpose of advocacy is to ensure everyone is treated equally and fairly and that their voices are heard.” P2

4.2 What are the common challenges of accessing advocacy services from the viewpoint of a person with learning disabilities?

The concept of advocacy tends to pose many challenges due to the fact that it is a relatively new concept in Ireland. Nevertheless, some of the participants have expressed that advocacy has enhanced the quality of lives for some people with learning disabilities. However, people with learning disabilities still tend to be the most vulnerable group in the disability sector.

Below are the key challenges expressed by the participants, which we will now discuss:

1. Paradigm shift from the medical model to the social model of disability.
2. Lack of support from staff, family members etc.
3. Attitude problems
4. Communication
5. Lack of independent advocacy services.

4.2.1. *Paradigm shift from the medical model to the social model of disability:*

The paradigm shift from the medical model to the social model of disability has proven to be a significant challenge in terms of accessing advocacy services for people with learning disabilities. People with learning disabilities were traditionally perceived as a person with a medical condition up until the late 1990's. This is when advocacy initially emerged among services such as the Brothers of Charity.

The establishment of the disability rights movement and the independent living movement has enhanced the shift to the social model to a great extent. However, there appears to be no mention of people with learning disabilities involved in these movements in comparison to people with physical or sensory disabilities. This indicates that people with a learning disability still tend to be seen as people with a medical condition living in an institution.

Meanwhile, P3 indicates that people with learning disabilities were put into industrial schools or industrial homes which meant they were forbidden to challenge authority. "They just did as they were told and no questions asked." Even though there has been a major shift from institutionalised care to community care, P1 indicates that these people who have lived in institutions all their life are now still afraid to challenge staff or anyone else in the community to access their basic rights. Similarly, P3 claims that staff who have been working with people with learning disabilities for years still work from an institutionalised frame mind. The participants indicate that there are still a certain number of people living institutionalised lives even though there has been dramatic change. This affects their prospects of getting access to advocacy services. The participants from the focus group and the self-advocate involved in this research emphasise that the shift from the medical model to the social model is essential in order for these individuals to get access to advocacy services in the community.

4.2.2. Lack of support

A major issue that was emphasised by all the participants has been a lack of support for people with learning disabilities to live independently in the community and speak up for themselves with the support of an advocate. In this research the people with learning disabilities involved, expressed their sincere disappointment pertaining to the lack of support from staff, family members and other professionals who may be working with them. P5 indicates that information and advice is a prerequisite of advocacy, but it is not always given to people with a learning disability, as some people such as staff tend to believe that they will not be able to understand.

Some of the responses reiterating the lack of support consist of the following:

- “In my experience there are many people with a learning disability whose lives have not changed. They have only got worse! This is due to the lack of advocacy services in the community.” P5
- “There is a lack of support from staff and PA’s to live independently in the community to make personal choice” P6

This is also evident in the literature and also from the centre for independent living conference discussed in chapter two.

4.2.3 Attitude problems

According to P5 and P6, some people in the community do not treat people with learning disabilities with equal respect and dignity that they deserve, due to a lack of awareness pertaining to disability. On the other hand, these two participants indicate that staff members and service providers find it difficult to change their attitude from the institutional way of thinking to the social model. Furthermore, P3 states: “people with learning disabilities have very little choice. Pretty much everything that happens in a person’s life is controlled by the service provider.”

4.2.4 Communication

Communication tends to be a common challenge for a majority of people with learning disabilities. This challenge is also apparent in some of the literature discussed in previous chapters. Meanwhile, P3 indicates that approximately two thirds of people with physical and sensory disability use the Galway Advocacy service whereas only one third of people with a learning disability use the service. “That does not mean that people with a learning disability don’t need advocacy, it’s because they are a little harder to reach.” P8.

It is apparent from the literature and the interviews that people with learning disabilities are by far the most vulnerable group in the disability sector. Given this, their need for accessing an advocacy service should be a high priority. However, this is not the case as people with learning disabilities are “not given the information and also some people have speech impediments which means they find it more difficult to speak up. Some responses relating to this challenge consist of the following:

- “The most obvious challenge is speech. A lot of people with learning disabilities are unable to verbalise their issues which can cause great frustration for these people.” P1
- “I think sometimes people make assumptions around disability that a person can’t communicate if they don’t communicate verbally.” P4

4.2.5 Lack of independent advocacy services

Accessing independent advocacy services was described as being the most difficult challenge for people with learning disabilities in comparison to the previous ones discussed. This is because historically advocacy has been offered from within a service provider. P8 indicates that getting access to an independent advocate can be difficult, especially for people with learning disabilities who live in residential care, as “they are very much in the power of the service provider.” P8.

Meanwhile, P3 recognises that the development of the community and voluntary sector independent advocacy projects, discuss in the previous chapter, have contributed greatly to a certain extent by providing advocacy outside the service provider. However, there are only a small number of people availing of the service.

4.3 What are the necessary actions required to enhance advocacy services for people with learning disabilities?

1. Promote self-advocacy
2. Provide more resources
3. Provide advocacy training
4. Ensure advocacy services are completely independent from service providers.

4.3.1 Promote self-advocacy

Self-advocacy appears to be the most effective form of advocacy for people with learning disabilities. This is evident from the literature and the responses from the participants. P5 has been a self-advocate for the past twelve years and it has enhanced her quality of life immensely. P3 emphasises the importance of self-advocacy and it needs to be promoted more among service providers to encourage the people who avail of their service to join a self-advocacy group in the community. Similarly, P7 stresses staff should support the service users in joining a self-advocacy group. Some of the responses expressed by the participants consist of the following:

- “I think first of all that peoples capacity to become self-advocates should become a priority. Then I think that the capacity should be brought into the community as apposed to just residing within the sphere of the institutionalised world.” P7

- ‘By being a self-advocate it is important to get the balance right between receiving an adequate level of support and people listening to you.’

It appears that self-advocacy is a key form of advocacy to enable people with learning disabilities to speak up for themselves. Furthermore, P7 believes that promoting self-advocacy is essential as it still “operates in the medical model.

4.3.2. Provide more resources

The participants for this research stress that there should be a greater number of advocates in the community in order to reduce the high level of inequalities and to enhance the quality of advocacy services for people with learning disabilities. On the other hand, P7 indicates that this will not happen at this point in time due to the current economic downturn. Unfortunately, this will have a significant impact on the provision of advocacy services for people with learning disabilities. Even though this point is recognised by most of the participants, they also express their concern regarding funding for advocacy provisions.

However, P5 and P6 expressed that advocacy is not all about money. There are some basic resources that should be available to enable people with learning disabilities to speak up for themselves or others. These resources consist of the following:

- “There needs to be more accessible [large print, Braille etc., information available for people with learning disabilities in relation to their rights and entitlements.” P5
- “We need support from staff and advocates to encourage us to speak up about our issues. We should not have to feel afraid to speak up.” P6

P5 and P6 have identified some of the resources and supports that do not require funding so it is essential that these resources should be provided preferably by an independent advocate.

4.3.3 Provide advocacy training

The participants believe that providing advocacy training would benefit many people with learning disabilities who are unaware that advocacy exists. This will provide an opportunity for these people to get access to information pertaining to their basic rights and entitlements. However, for this to be effective and to ensure that this opportunity is communicated to everyone, P5 stresses that staff must support this action and encourage people to participate. This kind of training can “empower people to be advocates for themselves. That’s really where you’re going to give people the chance to voice their opinions.”

4.3.4 Ensuring advocacy services are completely independent from service providers

This was one of the key actions identified by most of the participants, as it is vital to have independent advocates supporting people with learning disabilities in order to reduce the level of conflict between staff and the person with a disability. Furthermore, P6 indicates that this is a common issue for them as staff tend to be more concerned for their safety as if it’s a medical condition rather than offering them choices. Some of the responses reiterated by the participants indicate the importance of this action. These consist of the following:

- “There needs to be more independent advocates and they need to be completely independent. If the organisations would change and become a little more open and willing to be questioned, criticised and challenged by their service users that would be a huge improvement.” P3

- “Independent advocates encourage people to achieve their full potential more so than staff.” P5

It is apparent from this research that independent advocacy services play a pivotal role for people with learning disabilities in order to minimise the level of conflict of interest between service providers. This appears to be most important action out of the four discussed as it provides a great level of independence in the community.

4.4 Conclusion

This chapter discussed the overall findings of this research presented by the participants involved. Firstly, we discussed the concept of advocacy by presenting some of the broad definitions and purpose of advocacy reiterated by the participants. Secondly, we identified and discussed the main challenges of advocacy for people with learning disability and finally we identified and discussed the necessary actions required to enhance the quality of advocacy services for people with learning disabilities.

It is evident from this research that advocacy is a broad spectrum and there tends to be many issues around what it actually is, which is also clear from the challenges presented in the literature and the interviews.

The finally chapter will identify some key recommendations for further research and we will also conclude this dissertation.

Chapter 5:

Recommendations and Conclusions

5. Introduction

This chapter will identify some key recommendations for further research in this area of advocacy for people with learning disabilities in Ireland and finally we will outline the conclusions of this dissertation.

5.1 Recommendations for further research:

Some key recommendations for further research consist of the following:

- The qualitative research for this research consisted mainly of participants from the Brothers of Charity and the Citizens Information Board. A future recommendation would be to involve more participants from other learning disability organisations in order to give a more comprehensive insight to the concept of advocacy in Ireland.
- Self-advocacy tends to be an important form of advocacy. A possible idea would be to look at the effects of self-advocacy for people with physical, sensory and learning disabilities in Ireland.
- Independent advocacy services should be explored in more depth in terms of the pros and cons of the services in comparison to service providers providing advocacy services within the organisation.
- People with disabilities should be involved in the research as it is a powerful tool by means of providing accessible information and also empowers the individuals.

5.2 Conclusions:

This dissertation explored the concept of advocacy for people with learning disabilities in Ireland.

As advocacy is a relatively new concept, the dissertation began by identifying and discussing three definitions of advocacy.

Chapter one identified and discussed the main types and principles of advocacy that applies to all advocates both national and internationally.

Chapter two explored the development of advocacy from an international level to a national level.

Chapter three explored the development of advocacy in Ireland since the establishment of the Citizens Information Board (CIB) in 2000.

Chapter four presented the overall findings of this research which involved discussing the data that derived from the qualitative research.

This area of research is relatively new in Ireland. The main aim was to cover the key points regarding the concept of advocacy for people with learning disability. Atkinson (1999) carried out a similar project in England except his research focused on service provision of advocacy for all people with disabilities, whereas as this research focuses solely on people with learning disabilities covering the types and principles of advocacy and the development of advocacy both nationally and internationally.

This research clarifies that advocacy is a broad spectrum and tends to be widely misunderstood by many professionals among the multidisciplinary team in the disability sector in Ireland. Having explored the development of advocacy both nationally and internationally, it appears that advocacy is a relatively new concept in Ireland in comparison to the UK and the USA.

It is apparent that advocacy has enhanced the quality of life for many people with learning disabilities to a certain extent. However, this research indicates that people with learning disabilities tend to be the most vulnerable group among the disability sector in Ireland. Furthermore, people with learning

disabilities face many challenges when trying to get access to advocacy services. This has proven to be extremely difficult for many people with learning disabilities.

Finally, this research identifies a number of actions required to enhance the quality of advocacy services for people with learning disabilities. The most important action that has been reiterated through literature and the qualitative research is to ensure that independent advocacy services are completely independent from service providers.

An overall conclusion to this dissertation is that people with learning disabilities need to be given the opportunity to speak up regarding their basic rights and entitlements. Even though there has been many developments in advocacy up to date, there is still along way to go before all people will learn.

Bibliography

Books

Blanck, P. (2005). *Disability Rights: International Essays*. England: Ashgate Publishing Ltd.

Goodley, D. (2000). *Self-Advocacy in the Lives of People with Learning Difficulties: the politics of resilience*. Buckingham: Open University Press.

Grant, G., Goward, P, Richardson, M, Ramcharan, P (eds) (2005) *Learning Disability: A Life Cycle Approach to Valuing People*, Berkshire: Open University Press

Gray, B., Jackson, R. (2002). *Advocacy and Learning Disability*. London: Jessica Kingsley Publishers Ltd.

Lishman, J (ed) (2005) 'Empowerment and Advocacy' cited in *Handbook for Practice Learning in Social Work and Social Care: Knowledge and Theory*, London: Jessica Kingsley Publishers.

Morris, J. (1993). *Independent Lives – Community care and Disabled people*. London: Macmillan Press Ltd.

O'Brien. J. (1987). *Learning from Citizens Advocacy Program*. Atlanta, GA: Georgia Advocacy Office

Quin, S., Redmond, B. (Ed) (2003). *Disability and Social Policy in Ireland*. Dublin: University College Dublin Press

Ramcharan, P., Roberts, G., Grant, G., Borland, J. (ed) (1997). *Empowerment in Everyday Life: Learning Disability*. London: Jessica Kingsley Publishers Ltd.

Stone, K. (1999). *To Stand Beside – The Advocacy for Inclusion Training Manual*. Melbourne: Stone and Associates.

Swain, J., French, S., Cameron, C. (2003). *Controversial Issues in a Disability Society*. Buckingham: Open University Press

Tufail, J and Lyon, K (2007) *Introducing Advocacy: The First Book of Speaking Up – A Plain Text Guide to Advocacy*, London: Jessica Kingsley Publishers

Reports

- Atkinson, D. (1999). *Advocacy: A Review*. York: The Joseph Rountreer Foundation.
- Carroll, D. (2007). *Report on the Inclusion Ireland AGM and Conference*. Clarion Hotel: Cork
- Browne, M., Hyland, S., Mac Eochaidh, G. (2007). *Advocacy Resource Officers Pilot Project*. Final Evaluation Report. Citizens Information Board: Dublin.
- Citizens Information Board (Revised 2007). *Advocacy Guidelines*. Dublin
- Citizens Information Board (2002). *Developing Advocacy Services: Regional Fora report*: Dublin.
- Birmingham, D. (2001). *Advocacy: A Rights Issue*. Dublin: Forum of People with Disabilities. Dublin.
- Brothers of Charity Services (2007). 'Self-Advocacy/Citizens Advocacy.' Annual Report: Galway pg. 22
- European Living Community Living (2008). *Creating Successful Campaigns for Community Living: An Advocacy Manual for Disability Organisations and Service Providers*. ECCL.
- Goodbody Economic Consultants (2004). *Developing an Advocacy Service for People with Disabilities*. Dublin: Comhairle.
- Lundstrom, L. (2008). *Mapping Self-Advocacy Initiatives for People with Intellectual Disability in Ireland*. Dublin: Citizens Information Board (CIB).
- McCarthy, J. (2009). *Bord Snip Nua Report*. Dublin.
- National Disability Authority (2003). *Exploring Advocacy*. Dublin.
- National Federation of Voluntary Bodies (2007). *People Connecting: Findings from the 26th June 2006 Consultative Workshop on the Barriers, Incentives and Solutions to Community Participation and Inclusion of People and Intellectual Disabilities together with Recommendations to the Board of the National Federation*. Oranmore, Galway.
- People with Disabilities Ireland (2004). *Advocacy – The Future*. Dublin
- Weafer, J. (2003). *The Jigsaw of Advocacy*. Dublin: Comhairle

Strategic Plans

Carmichael House Strategic Plan (2009 –2012). *Centre for Independent Living*. Dublin: Board of Directors and the Strategic Planning Steering Team.

Centre for Disability, Law and Policy (2008 – 2012). *Strategic Plan*. National University of Ireland, Galway.

Disability Action Plan (2006 – 2015). *A plan about how to make things better for people with Disabilities in Europe – Easy to Read Version*: Council of Europe.

Inclusion Ireland Strategic Plan (2007 – 20012). *Making Inclusion A Reality*. Dublin

National Disability Authority (2007 – 2009). *Strategic Plan*. Dublin.

People with Disabilities Ireland (2003 – 2006). *Strategic Plan*. Dublin.

Newsletters and Newspaper articles

Comhairle (March 2004). *Speaking Up for Advocacy*. Dublin: 2(2)

Comhairle (October 2004). *Speaking up for Advocacy*. Dublin: 2(3)

Comhairle (May 2005). *Speaking up for Advocacy*. Dublin: 2(4)

Comhairle (November (2005). *Speaking up for Advocacy*. Dublin: 5.

Comhairle (March 2009). *Speaking up for Advocacy*. Dublin: 11

Disability Federation of Ireland (August 2009). *Government must not Abandon its commitments to People with Disabilities*. Dublin.

O'Brien (2008). Government urges to ratify. Irish Times

Journal Articles

Dowse, L. (2001). 'Contesting Practices, Challenging Codes: self-advocacy, disability politics and the social model. *Disability and Society*. 16(1): 123-141.

Flynn, E. (February 2009). *Rights-Enforcement for People with Disabilities – A Comparative study of Statutory Advocacy services in Ireland and Victoria*. Paper presented at the Irish Society of Comparative Law Conference, University of Limerick.

Flynn, E. (2009). 'A Socio-Legal Analysis of Advocacy for People with Disabilities – Competing Concepts of 'Best Interests' and Empowerment in Legislation and Policy on Statutory Advocacy Services.' *Submitted to the Journal of Social Welfare and Family Law*.

Flynn, E. (2007). 'Access to Services for People with Disabilities.' *Cork Online Law Review*. 2

Giles, M. (1997). 'Galway Citizens Advocacy Services.' *FRONTLINE*. Vol. 32. 22-23.

O' Callaghan, M. (2009). 'Ballyfermot Advocacy Service.' *Equality News*. Spring issue.

Woods, M. (2004). 'Speaking up for Advocacy.' *Equality News: Spring Issue*. 11 – 12.

Websites

Carmichael House CIL: www.dublincil.org (Accessed on 11/7/09)

European Network for Independent Living: www.enil.eu (Accessed on 2/7/09)

Galway Advocacy Service. <http://www.galwayadvocacyservice.ie> (Accessed on 12/6/09)

Inclusion Ireland Advocacy Projects:
<http://www.inclusionireland.ie/projects.asp>

Independent Living Institute: www.independentliving.org (Accessed on 12/6/09)

National Disability Authority: www.nda.ie.

National Federation of Voluntary Bodies Introduction:
<http://www.fedvol.ie/Introduction/Default.758.html>

One for Us: www.oneforus.com/Advocacy.32.0.html (Accessed on 12/6/09)

Conference

National Conference for Centres of Independent Living. 11th July, 2009. Harbour Hotel, Galway.

Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission for Social Development, August 2000: Farrell, M. (2008). 'Making them work for People with Disabilities.' Talk given at Brothers of Charity Human Rights Training: 15th May 2008, Days Hotel Galway.

Legislation

UN Convention on the Rights of Persons with Disabilities

American with Disabilities Act 1990

Citizens Information Act 2007

Comhairle Act 200

National Disability Authority Act (19

Appendix

Interview Questions

Participant 1: Staff member – Brothers of Charity Galway.

Type of interview Email

Questions:

1. What is your understanding of advocacy and what would you consider the main purpose of advocacy?
2. From your experience, what are the challenges of advocacy for people with learning disabilities?
3. What advocacy activities are your service users involved in?
4. Are you aware of any advocacy services in the community outside the organisation?
5. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
6. Are you familiar with the National Advocacy Council within the organisation?
7. Finally, do you have any further comments regarding this research?

Participant 2: Staff member – Brothers of Charity Waterford

Type of interview: Face to face interview

Questions:

1. What is your understanding of advocacy and what would you consider the main purpose of advocacy?
2. From your experience, what are the challenges of advocacy for people with learning disabilities?
3. What advocacy activities are your service users involved in?
4. Are you aware of any advocacy services in the community outside the organisation?
5. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
6. Finally, do you have any further comments regarding this research?

Participant 3: Galway Advocacy Service – Independent advocate

Type of interview: Face to face

Questions:

1. What is your understanding of advocacy and what would you consider the main purpose of advocacy?
2. What are your thoughts on the current state funding of advocacy services in Ireland?

3. From your experience, what are the challenges of advocacy for people with learning disabilities?
4. What proportion of people with learning disabilities use the Galway Advocacy Service?
5. How are people referred to this service?
6. Can you give some typical examples of the cases you deal with on a daily basis?
7. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
8. I understand you are the Chair of the Irish Association of Advocates, which is a new organisation in Ireland. What do you feel the benefits of IAA will be to the development of Advocacy?
9. Finally, do you have any further comments regarding this research?

Participant 4: National Federation of Voluntary Bodies

Type of interview: Face to face

Questions:

1. From your experience, what are the challenges of advocacy for people with learning disabilities?
2. What level of support does your organisation give learning disability NGO's?
3. Are people with learning disabilities involved in any of your research projects?
4. What are your thoughts on the current state funding of advocacy services in Ireland?
5. From your experience, what are the challenges of advocacy for people with learning disabilities?
6. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
7. Finally, do you have any further comments regarding this research?

Participant 5: Self-advocate – Brothers of Charity Galway

Type of interview: Face to face

Questions:

1. From your experience, what are the challenges of advocacy for people with learning disabilities?
2. I am aware you are well known Self Advocate so can you tell me about some of your experiences as a Self Advocate and has it helped you in your life?
3. Is self-advocacy important?
4. From your experience, what are the challenges of advocacy for people with learning disabilities?
5. Are you aware of any Advocacy services in the community outside the organisation?

6. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
7. Can you tell me about your involvement in the National Advocacy Council within the organisation?
8. Finally, do you have any further comments regarding this research?

Participant 6: Service User Council – Brothers of Charity Galway

Type of interview: Focus Group

Questions:

1. From your experience, what are the challenges of advocacy for people with learning disabilities?
2. What terminology do you prefer? i.e. learning disability, intellectual disability
3. Is this group involved in any advocacy activities individual or in a group?
4. From your experience, what are the challenges of advocacy for people with learning disabilities?
5. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
6. Finally, do you have any further comments regarding this research?

Participant 7: Area Executive Officer – Citizens Information Board Galway

Type of interview: Face to face

Questions:

1. From your experience, what are the challenges of advocacy for people with learning disabilities?
2. What are your thoughts on the current state funding on advocacy services in Ireland?
3. From your experience, what are the challenges of advocacy for people with learning disabilities?
4. What proportion of people with learning disabilities use the Citizens Information Services for advice?
5. I am aware the CIB are evaluating the pilot advocacy projects. How is this being done?
6. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
7. Finally, do you have any further comments regarding this research?

Participant 8: Advocacy Officer – Citizens Information Board Dublin

Type of interview: Face to face

Questions:

1. From your experience, what are the challenges of advocacy for people with learning disabilities?
2. What are your thoughts on the current state funding on advocacy services in Ireland?
3. How was Comhairle initially established?
4. From your experience, what are the challenges of advocacy for people with learning disabilities?
5. What do you think can be done to enhance the quality of advocacy services for people with learning disabilities?
6. Finally, do you have any further comments regarding this research?